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ABSTRACT

This issue of the "NICHCY News Digest" presents several articles designed to help parents of children with disabilities to plan their estate to best meet the needs of these children. The issue begins with an overview of the topic that discusses the following aspects: how the type of disability affects estate planning; considerations involved in writing a will; how to start planning an estate: issues to consider; and four possible approaches to establishing a will. A second article describes the creation of a Special Needs Trust to ensure that a person with a disability receives necessary supplemental care in the future. A final article focuses on the Letter of Intent, written by parents or guardians to describe a child's background and lifestyle as well as the parents' wishes, hopes, and plans for the child's future. A listing of 21 print resources and 13 organizational resources that may be able to provide further advice and information is also included. (PB)

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NICHCY News Digest

Estate Planning

National Information Center for Children
and Youth with Disabilities
Washington, DC

Volume 2, Number 1, 1992

This issue of ***NEWS DIGEST*** focuses on one very important and often complicated issue that parents confront when they have a son or daughter with any type of disability: How to plan their estate to best provide for their child's future security. Parents may ask themselves: "What will our son or daughter do when we are no longer here to provide help when it's needed? Where—and how—will our child live? Will he or she have enough money to sustain a decent quality of life?"

Other questions parents may ask themselves focus on the estate planning process itself: "How do I know what I am planning is going to work? Do I have enough money to hire a lawyer and write a will? Do I even have anything to leave my children?"

These are very difficult questions for parents to consider—and difficult ones to answer. When a child has a disability—be it mild, moderate, or severe—parents have concerns about that child's future. This ***NEWS DIGEST*** is directed towards addressing these concerns. The information provided in this document is relevant both to families whose child is already independent or is expected to be so, and to families whose child will need moderate or extensive support or supervision throughout life.

As parents, you may have a tentative plan in the back of your minds that one day, in the near or distant future, you will write a will that leaves your son or daughter with a disability sufficient resources to make his or her life secure. Many of you may have already written such a will. Yet there are many things to know and consider when planning your estate. For example, bequeathing a person with a disability any assets worth more than $2,000 may cause the person to become ineligible for government benefits such as SSI and Medicaid. For many individuals with disabilities, the loss of these benefits would be a devastating blow. In addition to the cash benefits and medical coverage that would be lost, the person would also lose any number of other government benefits that may be available to eligible persons with disabilities, such as supported employment and vocational rehabilitation services, group housing, job coaches, personal attendant care, and transportation assistance. Therefore, it is our hope that you, as parents, will read and thoroughly consider the information presented in this issue. The future security of your son or daughter with a disability may well depend upon the actions you take to establish an estate plan appropriate to your child's needs.

The first article in this ***NEWS DIGEST*** provides an overview of estate planning for parents of an individual with a disability. The second article describes how parents can create a *Special Needs Trust* and how this trust can be used to ensure that the person with a disability receives the supplementary care needed in the future. The third article focuses upon the *Letter of Intent*, a document that parents write to describe their son or daughter's background and present lifestyle and their own wishes, plans, and hopes for that individual's future. Often written in collaboration with the son or daughter, this letter is intended to provide future caregivers with insights into the person with a disability, which permits informed care to be given immediately, should anything happen to the parents. This ***NEWS DIGEST*** concludes with a listing of organizations and books that can provide readers with further information.

While we have endeavored to present useful and accurate information, you should be aware that laws and procedures are constantly changing and that ***this NEWS DIGEST is not a substitute for seeking expert advice.*** To formulate a legally valid estate plan, you will need the services of a professional familiar with estate planning, preferably one who has expertise in planning for parents of persons with disabilities. Only through these services can you be assured that your son or daughter has been provided for in the most secure way possible.

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Overview of Estate Planning Issues

by
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When parents have a son or daughter with any type of disability, they must plan their estates carefully to best benefit that child. How parents leave their assets after death may greatly affect the quality of life for their son or daughter with special needs. This article presents basic information to help parents begin considering the very important issues involved in developing an estate plan when the future of a son or daughter with a disability must be taken into account.

Many families believe that they have so few assets that an estate plan is not necessary. This is not true. We often have more assets than we realize, although some assets may become important only after our death. The most notable asset of this type is life insurance. Therefore, whether you consider yourselves a family of substantial means or with little or no assets, estate planning should be done.

How the Type of Disability Affects Estate Planning

Disabilities, of course, can take many forms and have varying degrees of severity. The nature and severity of your child's disability will affect the nature of the estate plan that you, as parents, develop.

Physical disabilities or health impairments. Many individuals have physical disabilities or health impairments that do not affect their ability to manage financial or other affairs. If your son or daughter has such a condition, how to leave your estate depends on a number of factors. The primary factor will be whether or not your son or daughter receives (or may one day need to depend on) government benefits such as Supplemental Security Insurance (SSI), subsidized housing, personal attendant care, or Medicaid. If your child *does* receive (or may one day need to depend on) government benefits, then it is most important to create a special estate plan that does not negate his or her eligibility for those benefits. How to do this is discussed in some detail in this ***NEWS DIGEST***.

On the other hand, you may have a son or daughter with a physical disability or health impairment who is *not* eligible for or who is not receiving government benefits. In this case, you may be able to dispense with elaborate planning devices and merely leave your child money outright, as you would to a nondisabled child. If you believe that the disability may reduce your son or daughter's financial earning capability, you may want to take special care to leave a greater portion of your estate to this child than to your nondisabled children.

There are some exceptions to this simplified approach, of course. One exception is when parents are somewhat fearful of their son or daughter's financial judgement. If you are concerned that your son or daughter with a disability may not responsibly handle an inheritance, then you can utilize a trust, just as you would for a nondisabled heir. Another exception is if your child's disability or health impairment involves the future possibility of deteriorating health and more involved health care needs. While your son or daughter may be capable of earning money and managing an inheritance at present or in the immediate future, in twenty or thirty years time deteriorating health may make it difficult for him or her to maintain employment or pay for health care. Government benefits might then become critical to your child's security. Remember, benefits include much more than money; your child may also be eligible for valuable services such as health care, vocational rehabilitation, supported employment, subsidized housing, and personal attendant care. If, however, he or she acquires too many assets through inheriting all or part of your estate, he or she may be ineligible for these benefits. Therefore, in order to protect your son or daughter's eligibility for government benefits at some point in the future *and* to provide for his or her long-range needs, you may need to consider establishing a special estate plan.

Special Note

Throughout this ***NEWS DIGEST***, you will see phrases such as "your child with disabilities," "children with disabilities," or "parents of children with disabilities." We have used the words "child" and "children" to simplify reading, but this does not imply that we are speaking only of young children. Indeed, we are speaking of individuals of all ages — young children, adolescent children, and adult children. At age 5, 21, or 45, "your child" remains your child, your offspring. He or she may be living independently, in a group home, with a relative or friend, or with you. Regardless of the age of your son or daughter, estate planning to provide for his or her future needs is important.

Cognitive disabilities or mental illness. If your son or daughter's disability affects his or her mental capability, the need to create a special estate plan is more clearcut. Mental illness and cognitive disabilities often impair a person's ability to manage his or her own financial affairs, while simultaneously increasing financial need. As a result, you must take care to ensure that there are assets available after your death to help your son or daughter, while also providing that the assets are protected from his or her inability to manage them. More information will be given later in this article about various ways to accomplish this. First, however, let us take a look at some basic information about wills and why a will is so important.

Writing a Will

All parents, but particularly parents of individuals with disabilities, should have a will. The object of the will is to ensure that all of the assets of the deceased parent are distributed according to his or her wishes.

If at death you have no will, your property will be dispersed according to the law of the state in which you live at the time of your death. This law is called the state's *law of intestacy*. Although laws of intestacy vary from state to state, in general they provide that some percent of assets of the decedent passes to the surviving spouse and the rest is distributed to the children in equal shares. Writing a will is highly recommended, since the laws of intestacy are rarely the most desirable way to pass property to one's heirs.

Although it is theoretically possible for any individual to write a will on his or her own, it is unwise to do so. Because of the technical nature of wills, it is highly advisable to have a lawyer prepare one. Parents of individuals with disabilities particularly need legal advice, because they often have special planning concerns. If you do not have a lawyer, you can call the local bar association, which will provide you with the name of an attorney in your vicinity. It is preferable, however, to contact a local disabilities group, which may be able to put you in contact with an attorney familiar with estate planning for parents of persons with disabilities. Not all lawyers are familiar with the special needs associated with caring and providing for individuals with disabilities. Before you hire a lawyer, be sure to find out if he or she has ever prepared estates for other parents who have sons or daughters with disabling conditions. If the lawyer has not, it is best to find a more experienced attorney. The cost of an attorney varies according to the attorney's standard fee and the complexities of the estate. The attorney can quote you a price based upon an estimation of the work. If the price quoted is beyond your immediate means, it may be possible to negotiate a payment plan with the attorney, whereby you pay over time.

"Be sure to find out if (the lawyer) has ever prepared estates for other parents who have sons or daughters with disabling conditions."

When making a will, however, remember that not all the assets you control are governed by a will. Joint property with right of survivorship, for example, passes independently of a will. If, for example, Tim and Sarah own a house as joint owners with rights of survivorship, upon Tim's death Sarah automatically inherits the house without regard to what Tim's will might say. Similarly, life insurance is paid out to the named beneficiary without regard to the will. The insurance is a contract between the owner and the insurance company, and the insurance company must pay the insurance to whomever the owner states. Many individuals have death benefits under an employer-provided pension plan. These, too, are not governed by the will but are paid to whomever the employee has designated. (Note: If you create a special estate plan to provide for your child with a disability – in particular, if you set up a special needs trust – review any life insurance policies you have purchased, and be sure that you have not designated your child as a beneficiary. The same is true for relatives who may have designated your child as the beneficiary of their policies.)

Personal property, such as clothing, furniture, and household effects, should be distributed by the will independently of the often more valuable assets such as stocks, bonds, and real estate. Personal property is often of great sentimental importance, but may have little financial value. To avoid disharmony after the death of the last parent, it is generally a good idea to make an equal division of the personal property among the children. *In some cases, the parents may wish not to include the child with the disability in the division, particularly if that might disqualify this person from government benefits.* However, in most cases it is advisable to leave the person with a disability a share of the personal property so that he or she does not feel excluded.

Remember, a will goes into effect only upon the death of the person who created it. Until death, the creator of the will can freely revoke, alter, or replace it.

How To Start Planning Your Estate: What to Consider

When parents have a son or daughter with a disability, they should give careful consideration to developing an estate plan that provides for that person's future best interests. Here are some suggestions that can help parents approach planning their estate when a son or daughter with a disability must be taken into consideration.

First: Realistically assess your son or daughter's disability and the prognosis for future development. If necessary, obtain a professional evaluation of your child's prospects and capability to

earn a living and to manage financial assets. If your son or daughter is already an adult, you should have a fairly clear understanding of his or her capabilities. But if your child is younger, it may be more difficult to predict the future. In such cases, you should take a conservative view. It is better to anticipate all possibilities, good and bad, in such a way that you do not limit your loved one's potential or set him or her up for unrealistic expectations. Remember, too, that you can change your estate plan as more information about your child becomes available.

"Remember that you can change your estate plan as more information about your child becomes available."

Second: Carefully inventory your financial affairs. Estimate the size of your estate (what you own) if you should die within the next year or the next ten years. Keep in mind that the will you write governs your affairs at the time of your death, and so it must be flexible enough to meet a variety of situations. Of course you can always write a new will, but you may never actually write it due to hectic schedules, procrastination, or oversight. Thus, the will you have written must have sufficient flexibility to meet life's everchanging circumstances.

Third: Consider the living arrangements of your son or daughter with a disability. Your child's living arrangements after your death are of paramount importance. Every parent of an individual with a disability should give thought to the questions, "If my spouse and I should die tomorrow, where would our child live? What are the possibilities available to him or her?" The prospective living arrangements of your son or daughter will have a tremendous impact on how your estate should be distributed. Involved in answering the question of living arrangements is whether or not your child will need a guardian or conservator to make decisions for him or her after your death. If you conclude that a guardian or conservator is necessary, you should be prepared to recommend a potential guardian or conservator in your will.

Fourth: Analyze the earning potential of your son or daughter. It is important to determine how much your child can be expected to contribute financially, as a result of employment. If he or she is currently employed, does this employment meet all of his or her living expenses, or only some? If your child is presently too young to be employed, you will have to project into the future. In many cases, even if your son or daughter is employed or expected to be employed at some point in the future, he or she will require additional financial assistance.

Fifth: Consider what government benefits your son or daughter needs and is eligible to receive. Support for a person with a disability will usually come from state and federal benefits. These might be actual case grants, such as social security or supplemental security income, or they might be in-kind support programs, such as subsidized housing or sheltered workshop employment.

In brief, government benefits can be divided into three categories. First are those categories that are unaffected by the financial resources of the beneficiary. For example, social security disability insurance (SSDI) beneficiaries receive their benefits without regard to financial need. Regardless of what the parents leave to a son or daughter with a disability, the social security payments will still be forthcoming once the person has qualified for them.

Second, some government benefits, such as supplemental security income (SSI) and Medicaid, have financial eligibility requirements. If a person with a disability has too many assets or too much income, he or she is not eligible to receive any or all of these benefits. Someone who *is* eligible due to a lack of financial resources can become *in*eligible upon inheriting money, property, or other assets. This would lead to a reduction or termination of the SSI benefits for that person. Therefore, if your son or daughter is receiving government benefits that have financial eligibility requirements, it is important to arrange your estate in a manner that will minimize his or her loss of benefits, especially SSI or Medicaid.

Finally, there are government programs available to individuals with disabilities where payment for services is determined according to the person's *ability* to pay. Many states will charge the individual with a disability for programmatic benefits if he or she has sufficient assets or income. The most striking is the charge that can be levied against residents of state mental institutions. For example, if a resident of a state hospital inherits a substantial sum of money, the state will begin charging the resident for the cost of residency in the state hospital and will continue to charge until all the money is exhausted. Yet the services provided will be no different from the ones that he or she was previously receiving.

Establishing a Will: Four Possible Approaches

Having decided what your son or daughter needs and what you own, you can now consider how best to assist him or her. There are four possible ways to do so.

First, you can disinherit your son or daughter with the disability. No state requires parents to leave money to their children, disabled or not. If your assets are relatively modest and your son or daughter's needs relatively great, the best advice may be to disinherit your child by name and have him or her rely upon federal and state supports after your death. This may be the wisest decision, particularly if you wish to help your other children. Instead of complete disinheritance, you might leave your son or daughter with a disability a gift of modest but sentimental value, such as his or her bedroom furniture. The value of the gift will be small enough not to affect

government benefits, but it will indicate your love and concern.

Second, you can leave your son or daughter with a disability an outright gift. For example, suppose your son Tom has a physical disability. You might write a will that states, "I leave one-third of my estate to my son, Tom."

If your child with a disability is not receiving (and is not expected in the future to need) government benefits, this may prove to be a desirable course of action. Your son or daughter, if mentally competent, can hire whatever assistance he or she needs to help with managing the gift. But if your son or daughter has a mental illness or cognitive disability, an outright gift is never a good idea, because this person may not be able to handle the financial responsibilities. If you want to leave a gift to support your child, the use of a trust is far preferable.

Third, you can leave a morally obligated gift to another of your children. Suppose, for example, that the parents have two children: James, who has mental retardation, and Mary, who has no disabilities. The parents leave all of their assets to Mary. Legally, Mary now owns all of the parents' assets and James owns nothing. But prior to their deaths, the parents told Mary that, although they are leaving everything to her, they expect her to use at least half of the money to assist James in whatever way Mary thinks best. They left the money to Mary, because they do not wish James to lose his government benefits, and they think that there are ways that Mary could use the money to help her brother. For example, Mary might provide special gifts to James on holidays or pay for special assistance for James that would not be provided by the government benefit programs. The gift is a moral obligation to Mary, because legally she can ignore the parents' wishes and do whatever she wants with the money: It is hers. It is only her conscience that guides her. After the parents' death, if Mary chooses to ignore James and use the money for herself, there is nothing James or anyone else can do about it. Morally obligated gifts are often used by parents with modest-sized estates for whom a trust does not seem desirable. The danger of morally obligated gifts is, of course, that the morally obligated recipient – in our example, Mary – may ignore the wishes of the parents. Even if Mary does not deliberately ignore the obligation, she may encounter circumstances that make it impossible for her to carry out her parents' wishes. Suppose, for example, that Mary or her children become ill or are in great financial need. She may feel under pressure to use the money for her own family, even if it means that James goes unhelped. Moreover, if Mary dies before James, it is possible that Mary's family will not carry on the duty to help James. Finally, in case Mary is divorced, the money may be lost to her former spouse in a settlement.

Morally obligated gifts, therefore, are not a complete solution. They can be useful, however, especially when the parents have a modest amount of money and do not expect a lifetime of care for their son or daughter with a disability. Rather, they merely want their nondisabled sons or daughters to use some of the inherited money to assist their sibling with special needs.

Fourth, you can establish a trust for your son or daughter with a disability. For many parents who have a child with disabilities, the use of a trust is the most effective way to help that individual. The point of a trust is to keep assets in a form that will be available to your son or daughter but that will not disqualify him or her for government benefits for which he or she might otherwise be eligible.

The next article in this ***NEWS DIGEST*** discusses in some detail what a trust is, the circumstances under which a trust is advisable, and issues to consider when establishing a trust.

In A Parent's Words

It had been in the back of my mind for years, soon after I found out my son Samuel had this lifelong disability. What would the future hold for him when I wasn't there anymore to be his advocate, friend, and supporter? It was both a big and little worry. Big, because it gave me a hole in my gut whenever the questions crept in. And little, in the sense that I tried not to think about it. I'd think: I'll worry about that tomorrow, next week, when he's older, when *I'm* older.

Of course, I've done things to prepare Samuel for that future he's going to have without me, things like teaching him how to wash clothes and shop. But could I write a will? Make an estate plan? No, for years, I dodged that one totally.

Then, when his voice started to change, it suddenly hit me that he was growing up, that he was older *now*. That future I was always worrying about, and refusing to worry about, was beginning to arrive. I talked with my husband, and I found out he'd been worrying about Sam's future, too. So he and I went to our lawyer. I was so nervous, to bring all the questions out in the open and look at them. No wonder I'd shoved them under the bed for so long!

But you know, it's funny. Now that we're finished setting up our estate and only need periodically to review our plans, I feel like an enormous burden has been lifted up from me. The big, black, scary shadow is gone. Well, not totally gone, I suppose. I still worry about Samuel, what will happen to him in his life. I guess every parent does that. But now I don't worry in the same way. I know I've done all I can do for *that* part of his future, something that was extremely important to do, and I am very relieved. Now I feel like we can deal fully with the present day and see to the other things that need to be done to prepare Samuel for life as a man. And that's very exciting.

The Special Needs Trust

by
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Imagine for a moment that one evening, on your way home from a movie or a dinner party, you and your spouse pass away in an automobile accident. While you were always planning to write a will, you never actually got around to it, so your modest estate, including some life insurance, is distributed by the laws of your state. You have two sons, one with a disability and one without. Each of your sons inherits $100,000.

Your older son, Frank – who does not have a disability – uses his inheritance to pay off some of his mortgage and splurge on a new car. In contrast, your younger son Johnny gains nothing and loses much. Johnny, who has multiple disabilities, does not work and relies solely on government benefits for housing and medical care. The inheritance causes Johnny to lose those benefits. He must now provide for his own medical care, which includes the considerable cost of medicine, personal care attendants, physical therapy, and doctor's visits. The group home in which he lives begins to charge him for residency and for the services he receives there. Within two years, all but $2,000 of the inheritance is gone. At this point Johnny again becomes eligible for government benefits and is re-instated after a waiting period of several months – a period in which he uses up the last of his inheritance. Now there are no funds left to pay for whatever supplemental needs Johnny might have: education, over-the-counter medicines, dental care beyond what is covered by government benefits, trips to see his brother or other family members, reading materials, supplies such as razors, soap, and shampoo. Government benefits do not cover these types of expenses, and Johnny's parents are no longer here to do so. The irony of the situation is that, while an inheritance should ordinarily improve a person's lifestyle, this one has worsened Johnny's.

The Question of Relying on Government Benefits Only

The first question that comes to mind when something like this occurs is one of fairness. Should the government continue to subsidize someone who has "money?" On one hand, the standard government programs such as SSI and Medicaid were established to help persons who are elderly or who are disabled and living at the poverty level. On the other hand, government benefit programs are paid for out of tax dollars, and eligible individuals are entitled to receive these benefits.

When families consider this question, they should be aware that, while the services available through government benefit programs may be substantial (e.g., medical coverage through Medicaid), the actual cash benefits are generally quite small and force the individual to live way below the poverty level. In 1992, the maximum Federal SSI monthly payment was $422 for an individual. This means that, for an individual with a disability to have any type of meaningful lifestyle, the family or local charities have to provide supplemental assistance.

With recent changes in the Social Security Administration, the primary government benefit programs are recognizing that family contributions to the person's well-being can only improve his or her overall quality of life. As long as the family's contributions are supplementary in nature, as opposed to duplicating government benefit programs, they are permitted. Thus, the current government benefit programs *do* permit the family to provide some supplementary income and resources to the person with a disability. However, the government regulations are very strict, and they are carefully monitored.

Special Needs Trust

The only reliable method of making sure that the inheritance actually has a chance of reaching a person with a disability when he or she needs it is through the legal device known as a *Special Needs Trust* (SNT). The SNT is developed to manage resources while maintaining the individual's eligibility for public assistance benefits. How is this done? Simply put, the family leaves whatever resources it deems appropriate to the trust. The trust is managed by a trustee on behalf of the person with the disability.

While government agencies recognize special needs trusts, they have imposed some very stringent rules and regulations upon them. This is why it is vital that any family contemplating using a SNT consult an experienced attorney – not just one who does general estate planning, but one who is very knowledgeable about SNTs and current government benefit programs. One wrong word or phrase can make the difference between an inheritance that really benefits the person with a disability and one that causes the person to lose access to a wide range of needed services

and assistance. As an illustration of this, suppose that the trust instructed the trustee (manager) to pay the person with the disability $100 a month for life. Such a mandatory income might jeopardize government benefit programs, which only allow him or her to have $70 of income each month.

The first thing that may come to mind for most families who have had experience with government benefits is that the government says that a person with a disability cannot have a trust. Correct. However, the special needs trust does not belong to the person with a disability. The trust is established and administered by someone else. The person with the disability does *not* have a trust. He or she is nominated as a beneficiary of the trust and is usually the only one who receives the benefits. Furthermore, the trustee (manager) is given *the absolute discretion to determine when and how much the person should receive.*

Given the government's stringent requirements (see the box on the right), it is critical that the trust be carefully worded and show clearly that the trust:

- is established (grantor, settlor) by the family (persons other than the person with the disability);
- is managed by a trustee (and successor trustees) other than the person with the disability;
- gives the trustee the absolute discretion to provide whatever assistance is required;
- should never give the person with the disability more income or resources than permitted by the government;
- must be used for supplementary purposes only; it should add to the things provided by the government benefit program, not supplant (replace) them;
- defines what it means by supplementary/special needs in general terms, as well as in specific terms related to the unique needs of the person with the disability;
- provides instructions for the person's final arrangement (families should assume that when the individual with the disability dies no relatives will be alive who know what the mother and father would have wanted);
- determines who should receive the remainder (what is left over) of the trust after the individual with the disability dies;
- provides choices for successor trustees – people or organizations that might be able to take a personal interest in the welfare of the person with the disability; and
- protects the trust against creditors or government agencies trying to obtain funds to pay for debts of the person or the family.

Since the trust is a legal arrangement that is regulated by the laws of your state, there will be other sections that your attorney may need to insert. It is important to know that, while the majority of public assistance funds come from the federal government (which provides guidelines for SNTs), it is the responsibility of each state government to regulate trusts and administer the federal benefits. As long as the federal guidelines are followed to the letter, the state will accept the SNT, and the trust will fulfill its function.

Testamentary or Intervivos Trust: That is the Question!

At one time, the average attorney simply advised parents of an individual with a disability to prepare their Last Wills and Testaments and include a Testamentary Special Needs Trust. Upon the death of the parents, the wills would be probated, and the special needs trust would be created. In simpler days, this was pretty good advice.

Today, most attorneys who are experienced in estate planning for persons with disabilities will advise the family to prepare an *Intervivos Special Needs Trust. Intervivos* simply means that the trust functions *now*, while the parents are still living. As a "living" trust, it should not be confused with the modern estate planning tool for the family's main estate, the Family Revo-

What the Social Security Administration Has to Say About Special Needs Trusts

The Social Security Administration's (1990) publication *Understanding SSI* discusses special needs trusts as follows:

How do resources in this type of trust count in the SSI program?

Money or property in this type of trust for an SSI beneficiary... does not count toward the SSI resource limits of $2,000 for an individual.

How does money from the trust affect the individual's SSI payments?

Money paid directly to the providers for items other than the person's food, clothing, and shelter does not reduce SSI payments.(Items that are not " food, clothing, or shelter" include medical care, telephone bills, education, entertainment.)

Money paid directly to the providers for food, clothing, and shelter does reduce the individual's SSI payments — but only up to a limit. No matter how much money is spent for these items, no more than $155.66 (in 1991) is subtracted from the individual's SSI check.

Money paid directly to the individual from the trust reduces the SSI payment. (U.S. Department of Health and Human Services, 1990, p. 46)

cable Living Trust. These are two very separate trusts. The Family Living Trust is designed to avoid probate, reduce estate taxes, and make for a smoother estate distribution. The Intervivos Special Needs Trust's sole function is to look after the future of the person with the disability.

Parents need not wait until their son or daughter is 18 years old to establish the Intervivos Special Needs Trust; they can establish the trust now. The trust is set up as a checking account at a local bank. Families can place funds into the trust every month and use these funds to cover the normal supplementary expenses of the person with the disability, as well as to save for the future. Using the trust funds to pay for the individual's supplementary expenses is also an excellent way of recordkeeping, for these expenses are tax-deductible.

An Intervivos or Living Special Needs Trust has other very unique features, such as:

- It is a trust that is separate from the family's main estate.
- The trust is managed by the trustees, who are usually the parents.
- By paying for supplementary items from the checkbook, the family shows the future trustees the types of things that are appropriate to the person's needs and that have passed government scrutiny. The typical government challenge to a SNT comes when a trustee pays for nonsupplementary items. (In contrast, a testamentary trust – one that is created after the parents have died -gives guidelines on how to establish the trust; it does not give specific examples of how to administer it.) The simple checkbook with its stubs can help the future trustees use the Living Special Needs Trust properly and avoid expensive challenges.
- Often relatives (e.g., aunts and uncles, grandparents) would like to leave an inheritance to the person with the disability but are concerned that, if they leave it to the person, he or she will lose government benefits or will mismanage the funds. Relatives like the concept of a trust, which is a nice legal way to make sure the person actually receives the full gift. With a testamentary trust, the parents of the person with the disability must die, their estate must be probated, and then the trust will be created. After the trust is created, relatives can leave money to the trust. The better option is to create a living special needs trust NOW. This permits relatives with tax concerns (i.e., those who need to give money each year to avoid large estate taxes upon their death) to give money into the trust now, rather than only upon their deaths.

A Parent's Suggestion

Carol and her husband recently completed their estate plan so that their children would be provided for. They have twin sons who do not have disabilities and a son who has Down Syndrome. Here is what Carol has to say about the process of estate planning.

When my husband and I went to talk the lawyer, we hadn't really talked much among ourselves first. I thought that since we agreed on almost everything about caring for Frank, our son with Down Syndrome, we would be in agreement about how to provide for his future needs, when we weren't around anymore to care and advocate for him.

We found out, though, that we had different ideas. And we found out in the lawyer's office! Then we got home and found out our twins were hurt that we hadn't consulted them at all, had just assumed they wouldn't want to be responsible for helping Frank after we were gone. So then we did what we should have done before going to see the lawyer – we talked as a family.

So my advice to other parents is: Before going to the lawyer for the first time, talk among yourselves about the future and your ideas for how to provide for your son or daughter with a disability. Then talk to the lawyer. Then return home for more discussion within the family. Then continue working with your lawyer and financial planner to create a plan the family can feel comfortable with.

In today's society, it has been said that 40-60% of the population will go into a nursing home before they die. The average family's total estate will be completely used up in one year to cover nursing home costs. In their wills, the parents may have generously given everything to the testamentary trust. Unfortunately, after nursing home care and Medicaid expenses, there may be no estate left for the testamentary trust. Even if a portion of the estate remains after the parents die, there may be a six month to six year wait while the estate is being probated. A testamentary trust would not be created or funded during this waiting period. What would happen to the supplementary needs of the person during such a wait?

Having a living special needs trust creates a much more secure scenario for the person with the disability. With this type of trust, the parents would have saved money each month for the future and may have purchased life insurance or transferred assets into the trust. Should they suddenly pass away or have to go into a nursing home, the living trust, which is a private matter, continues to function without interruption. The successor trustee designated by the parents would begin to administer the trust funds within a short period of time (one to two

hours). Supplementary assistance to the person with the disability would continue without a break.

Revocable or Irrevocable?

Once the basic details of the trust have been agreed upon, you have to decide whether to lock the door and throw away the key, making it impossible to change the trust, OR to hold the key just in case you want to make some changes. With a *Revocable* trust, you retain the right to add and subtract assets as you go along. With this right, there are some potential consequences. The first and major consequence is that the government considers the trust to be part of your estate. Therefore, when you die, everything in the special needs trust is included in your estate for tax purposes and for potential lawsuits. What happens if someone sues your estate after you are gone? The assets in your special needs trust could be lost in such a lawsuit. Even if you only put a life insurance policy in the trust, it now reverts back to where your creditors and the IRS can lay claim.

If you make your trust *Irrevocable*, it means that any assets you place in it will remain there for the benefit of the person with the disability. If you need some of these assets later on for your own care, you cannot take them out. The advantages of an irrevocable trust may outweigh the disadvantages, as long as you do not place too much in the trust. If it is set up properly, it is completely separate from your estate. The irrevocable trust is considered a separate entity. It has its own tax number. Any assets that you place in the trust cannot be touched by your creditors for debts, taxes, and so on. Neither can the trust be touched by any creditors of the person with the disability.

What should you do? For younger parents, the answer may be a revocable trust. For older parents, the irrevocable trust may be the only option. Your attorney, in consultation with your financial planner, may be the best resource in making this determination. It is important, however, to have a current Letter of Intent (see article on page 11), which will help your trustee interpret the "legalese" of either the revocable or irrevocable trust in light of your hopes and desires for the future.

"The average family finds that they must rely on relatives or close friends to manage the trust funds."

Trustee: The Manager of Resources

It is one thing to leave resources to a trust, and it is quite another to manage them in such a way as to last the lifetime of the person with the disability. Every trust must have a *trustee*, someone who will manage the trust's assets. As most special needs trusts are established to provide supplementary assistance, they are generally quite small by bank standards. Ideally, it would be nice to have a local bank manage the trust resources, while taking a personal interest in the individual with the disability. Failing the location of a warm and loving trust officer, at least the bank would manage the funds and hire a social worker to look after the individual. Sadly, very few banks are willing to manage cash assets under $150,000 to $200,000 or become as involved in the person's life as you would wish.

In the case of a living trust and where there are sufficient funds and relatives, the family usually nominates future or *successor* trustees to manage the trust after the parents die or go into a nursing home. Families may even nominate a group of people to serve as joint trustees – several relatives, perhaps – who together administer the trust. It is important to list an advocacy or disability organization as the last successor trustee. This is because the possibility exists that the human successor trustees will die before the person with the disability. In the event that the human successor trustees are unable to serve, then the advocacy or disability organization may take on the responsibility or be able to recommend someone in their group who could do so. Of course, it is important to discuss this with the disability or advocacy group and obtain consent before listing the organization as a future trustee.

Master Trusts

The average family finds that they must rely on relatives or close friends to manage the trust funds. For many older parents with few surviving friends or relatives, the choice of a competent and caring trustee becomes very difficult or even impossible to find. The oldest son may be a fantastic, loving person to his sister with a disability, but may have difficulty managing his own finances, let alone the assets of the trust.

Many disability-related and other not-for-profit organizations have attempted to resolve this very serious problem by establishing *Master Trusts*. The individual special needs trusts are generally managed under the umbrella of a "master" or large trust fund. In this way, the family that may have only $50,000 or less to leave will have the assurance that the funds will be managed properly. The organization also promises to serve as an advocate for the person with the disability. Thus, the parents feel comfortable that someone will visit their son or daughter on a regular basis and look after his or her interests.

As the population grows older and develops nursing care needs, with family members living further apart, and with financial institutions becoming more conservative, the Master Trust may be the only real answer to the dilemma of small trust funds managed by people who actually care about persons with disabilities. Today, the average master trust in the United States is established by a local charity or nonprofit agency to serve persons with one or more disabling conditions. Occasionally, a few chari-

ties serving different populations will pool their resources to establish a community trust. A full-time executive director, along with a secretary, work with a Board of Directors. The prospective family pays approximately $500 to $2,000 to receive basic life planning counseling and as a set-up charge. The family generally hires an attorney recommended by the charity to do the basic legal work, which may cost from $500 to $3,000. The charity also refers the family to a reputable financial planner to make sure that the trust is funded properly. The master trust staff will usually meet with the family once a year to make sure that everything is in place. This annual "check-up" may cost between $50 and $100. Should the parent(s) go into a nursing home, the Master Trust can be activated. Assuming there are sufficient cash reserves in the trust, an advocate will look after the person with the disability. And upon the death of the parents, the trust will be fully activated through guaranteed life insurance proceeds or a portion of the family's estate. This is the ideal.

Unfortunately, although the concept of Master Trusts has been around for many years and may indeed represent the only viable answer to the need of many individuals with disabilities for lifelong care, Master Trusts have yet to find a proven formula for success. The track record for many of these types of trusts is very poor. Many are set up but fail within three to five years. Why do they fail? Although there are many reasons, basically the average master trust signs up only eight to ten individuals over the three-year start-up period, which is often funded by a grant. When the grant runs out, the Master Trust soon ends, in part because of the cost of hiring and keeping staff to manage the trust, but also because the eight to ten families were usually the key leaders of the organization and the strength of its membership. The majority of other members were never properly introduced to the merits of this fine program. Furthermore, the trust was created and managed by individuals who were primarily interested in the care of loved ones with disabilities, not in the business of marketing the trust to others. To work in the long term, the trust has to be sold in a businesslike, even aggressive manner.

Of course, not all Master Trusts fail. There are some that have operated successfully for many years. However, because the concept of a Master Trust has generally not proven successful, it is essential that families take a hard look at any Master Trust they are considering joining. Families should make sure that, if the trust does end, they have an escape clause whereby they can get back their assets.

"Most families are surprised to learn that they do have a variety of resources within their reach that can be directed to the Special Needs Trust."

Funding a Special Needs Trust

As families do their estate planning for their loved ones, they tend to think of it as a legal issue only. However, the lawyer can only establish the trust for them. Someone has to find the funds to put in it and make sure that there are sufficient funds to last the lifetime of the individual with the disability. That person is a financial planner.

The general perception of a financial planner is someone who is going to try to sell you investments and insurance through high pressure techniques. While the financial planner may very well use various financial products to fund the trust, the more reputable planners realize that most families have limited resources. Therefore, the planner's primary job is to help the family see what resources are available and then reallocate them, so that the future funding of the trust will be realistic.

As with attorneys, there are very few financial planners who have any experience with planning for the future of a person with disabilities. Most are trained to look at the overall family estate and try to provide as many dollars as possible, at the same time looking out for potential problems. When they realize that there is a person with a disability involved, they may react in a very human way, assume that the person will need extra help, and direct more dollars to the person with a disability, without understanding the consequences this might have in terms of the person's government benefits.

An experienced financial planner will examine your Letter of Intent (see page 11) and do a detailed financial analysis based on the future costs of supplementary items and advocacy. He or she will then look at the many different resources available to fund the trust now and in the future. (See the worksheet on page 12, which you can use to list the total monthly expenses of the person with a disability. When you subtract the total amount of government benefits and personal income of the person from the total monthly expenses, you have identified the amount of supplementary funds needed on a monthly basis by the person with a disability.) The only other major expense will be the cost of advocacy services, which may run from $50 to $100 per hour.

Most families are surprised to learn that they do have a variety of resources within their reach that can be directed to the Special Needs Trust. The options open to a family include:

- *Standard government benefits.* These benefits form the foundation for the future.
- *Savings.* No matter how you look at it, the family will have to SAVE for the future. The government benefit programs have never provided enough for even poverty level existence. A regular savings program is essential to meet the person's supplementary needs in the future.

- *Family assistance*. Family members may wish to provide residential care, supervision, and supplemental assistance in the future.
- *Parents' estate*. Parents may leave a portion or all of their estate to the trust. To keep peace in a large family, parents should leave something for the other children as well.
- *Inheritances*. Relatives or friends who have expressed an interest in the person with the disability should be given instructions and assistance on how to leave a gift to the trust.
- *Property*. Some families want their loved one to live in the same house. The house can be placed in the trust and managed by a local nonprofit agency for the benefit of the person, or expanded into a group home setting.
- *Investments*. Certificates of Deposit, IRAs, KEOGHs, and so on can be directed to the trust.
- *Military benefits*. Some families have elected a Survivor Benefit Option (SBO), so the person with the disability will always have some income and medical care. They may still want a special needs trust to manage the other resources which will supplement the military benefits.
- *Insurance*. For the average family, life insurance may be the only way that they can leave a large lump sum for the future by making small monthly payments. It is also one of the few guaranteed methods of funding a trust. While the above items may fizzle out as people change their minds or the economy falters, a paid-up life insurance policy in an irrevocable trust will guarantee future funds.
- *Other resources*. Many families have resources that are unique to them. The financial planner will help you determine which ones are appropriate for funding the trust.

As families examine ways to fund the trust, they need to keep in mind something very important. Do not forget the other brothers and sisters. While the siblings may be pillars of love and understanding when it comes to their brother or sister with a disability, they have probably seen a great deal of your time and energy spent in the disability arena. They should not be left out at the end. Families tend to assume that, while they must pay for the services of a bank trustee and a guardian/advocate, relatives who take on these responsibilities should do so for free, because that is what families do! The trustee should be directed to pay for whatever services are necessary, whether an agency or relative performs the service. This may mean the difference between a brother driving the fifty miles to his sibling's group home once a week or once every three months.

With proper legal and financial planning, the family can guarantee that the person with the disability will enjoy a comfortable lifestyle after the parents are gone.

The Letter of Intent

by
Richard W. Fee
Executive Director
Estate Planning for Persons with Disabilities

What is the Letter of Intent?

Simply put, the Letter of Intent is a document written by you (the parents or guardians) or other family members that describes your son or daughter's history, his or her current status, and what you hope for him or her in the future. You would be wise to write this letter today and add to it as the years go by, updating it when information about your son or daughter changes. To the maximum extent possible, it is also a good idea to involve your child in the writing of this Letter, so that the Letter truly "presents" and represents your child. The Letter is then ready at any moment to be used by all the individuals who will be involved in caring for your son or daughter, should you become ill or disabled yourself, or when you should pass away.

Even though the Letter of Intent is not a legal document, the courts and others can rely upon the Letter for guidance in understanding your son or daughter and the wishes of you, the parents. In this way, you can continue to "speak out" on behalf of your son or daughter, providing insight and knowledge about his or her own best possible care.

Why is it Important to Write a Letter of Intent?

A Letter of Intent serves many purposes. First, it spells out in black and white your son or daughter's background

(continued on page 13)

Worksheet for Costing Out Expenses of the Person with the Disability

This Person's Income

Government Benefits _____
Employment _____

TOTAL MONTHLY INCOME _____

This Person's Expenses

Housing:
- Rental _____
- Utilities _____
- Maintenance _____
- Cleaning items _____
- Laundry costs _____
- Other _____

Care Assistance:
- Live-in _____
- Respite _____
- Custodial _____
- Other _____

Personal Needs:
- Haircuts, beauty shop _____
- Telephone (basic, TT) _____
- Cigarettes _____
- Books, magazines, etc. _____
- Allowance _____
- Other _____

Clothing _____

Employment:
- Transportation _____
- Workshop fees _____
- Attendant _____
- Training _____
- Other _____

Education:
- Transportation _____
- Fees _____
- Books, materials _____
- Other _____

Special Equipment:
- Environment control _____
- Elevator _____
- Repair of equipment _____
- Computer _____
- Audio books _____
- Ramp _____
- Guide dog _____
- Technical instruction _____
- Hearing Aids/Batteries _____
- Wheelchair _____
- Other _____

Medical/Dental Care:
- Med/Dental visits _____
- Therapy _____
- Nursing services _____
- Meals of attendants _____
- Drugs, medicine, etc. _____
- Transportation _____
- Other _____

Food:
- Meals, snacks-home _____
- Outside of home _____
- Special foods _____
- Other _____

Social/Recreational:
- Sports _____
- Special Olympics _____
- Spectator sports _____
- Vacation _____
- TV/VCR or rental _____
- Camps _____
- Transportation _____
- Other _____

Automobile/Van:
- Payments _____
- Gas/Oil/Maintenance _____
- Other _____

Insurance:
- Medical/Dental _____
- Burial _____
- Automobile/Van _____
- Housing/Rental _____
- Other _____

Miscellaneous:
- Other _____
- Other _____
- Other _____

TOTAL EXPENSES _____

(Subtract)
MONTHLY INCOME + GOVERNMENT BENEFITS _____

(Equals)
SUPPLEMENTARY NEEDS _____

and history and his or her present situation. It also describes your wishes, hopes, and desires for his or her future care and, where possible, describes your *child's* feelings about the present and desires for the future. While you are still living, the Letter can be used by your lawyers and financial planners to draft the proper legal documents (wills and/or trusts) to ensure your wishes are carried out. Once you are no longer able to take care of your son or daughter, due to death or illness — and this is the most important reason to write a Letter of Intent — the Letter gives your son or daughter's future caregivers some insight into how to care for him or her. It provides advice on possible alternatives for his or her care. If your child has a severe disability, caregivers will not have to waste precious time learning the most appropriate behavior or medical management techniques to use. If your child is used to doing things independently and only requires occasional assistance, the Letter can spell out exactly what is needed. The Letter of Intent can describe this very concrete information and much, much more, including valuable information about the personality of your son or daughter — his or her likes, dislikes, talents, special problems, and strengths. Thus, the Letter is a crucial part of any life or estate plan, because it speaks both for and about the person with a disability and his or her family.

When Should Parents Write the Letter of Intent?

The answer is a simple one. Start now. Start today. Procrastination is easy, when your health is good, the future looks bright, and there are a hundred other pressing tasks to be done. But none of us can predict the future. What will happen to your son or daughter, if something happens to you? Will your relatives, friends, lawyer, or the police know where to contact your son or daughter - and will that person know enough about your loved one to know what kind of care is needed and how best to provide it?

Writing the Letter of Intent now is a way to protect your son or daughter from unnecessary chaos and turmoil when he or she must depend upon someone other than you for the care and support that is necessary. The Letter of Intent helps pave your son or daughter's transition by giving future caregivers the information about him or her that they so vitally need.

Preparing the Letter is often an emotional experience for parents and their children. You will need self-discipline and motivation to work past the many painful questions and issues that must be addressed when considering your son or daughter's future.

What Information Goes Into the Letter of Intent?

How can you summarize the life of a person you have watched grow and develop over many years? What can you say that will give insight into and perhaps touch the heart of a careprovider who must suddenly assume some measure of responsibility for your son or daughter?

Basically, the procedures for developing a Letter of Intent are fairly simple. You can write the Letter out longhand, or you can use a computer or typewriter. Don't worry about perfect spelling or grammar; your major concern is that anyone who reads the Letter in the future can understand exactly what you meant and what you would like to see happen in your son or daughter's life. Begin by addressing the Letter to "To Whom It May Concern." In the first paragraph list the current names, addresses, and telephone numbers of the people who should be contacted if anything should happen to you (i.e., other children, case manager, your son or daughter's school principal or employer, lawyer, financial planner, priest, etc.). You might then briefly state the family history; include names, birthdates, and addresses of family members.

The Letter will then need to focus in upon seven potentially major areas of your son or daughter's past, present, and future life. Depending upon your child's needs, these areas may be: housing/residential care, education, employment, medical history and care, behavior management, social environment, and religious environment. You might begin by summarizing your son or daughter's background and present status in each of these areas. Then summarize your wishes, hopes, and desires for his or her "best" future, listing three or four options in each of these areas. Be sure to discuss your ideas with your son or daughter and to take into consideration his or her feelings on the future (more is said about this below). The worksheet shown at the end of this article is useful for this "future planning" step, which may require much thought and planning before you actually begin to write information into the Letter of Intent.

Take a brief look at the example shown in the box on the next page. This example focuses on only one of the major life areas — Housing/Residential Care — and illustrates how a person named Mrs. Sanders went about writing this section of her Letter of Intent for her son named Chris, a 35 year old man with developmental disabilities.

How Do I Involve My Son or Daughter in Writing the Letter?

How much you involve your son or daughter in writing the Letter of Intent will depend in large part upon his or her age and the nature and severity of the disability. It is only fitting that young adults and adult children be involved in planning their own lives to the maximum extent possible. Many individuals have disabilities that do not prevent their full or partial participation in the Letter-writing process. Before involving your child, however, you, as parents, might want to talk first among yourselves about the content of the Letter and your ideas regarding your child's future. When you've agreed upon the basic information you feel should go in the Letter, discuss each area with your son or daughter. Ask for your child's input about his or her favorite things to do, what type of

education has been enjoyable and what might be pursued in the future, what type of employment he or she enjoys or envisions. Equally crucial to discuss are your child's future living arrangements: How does your child feel about the options you are considering listing in the Letter of Intent?

It's important that your child realize that the Letter is not a binding, legal document; it is written to give guidance, not edicts, to all those involved in caregiving in the future. If you fear that your child will be upset by talking about a future that does not involve you as parents, then you may wish to make the discussion simply about the future — what will happen when your child leaves high school or a postsecondary training program, what your child wants to be or do in the next ten years, where he or she wants to live. You may be surprised to find that discussing the future actually relieves your child. He or she may very well be worrying about what will happen when you are no longer there to provide whatever assistance is needed.

Involving your child in discussing and making decisions about the future may be more difficult if the individual has a disability that severely limits his or her ability to communicate or to judge between a variety of options. You, as parents, are probably the best judges of how much — and how — you can involve a son or daughter with a severe cognitive disability. For these children, the Letter is especially critical; it will serve to communicate the vital information about themselves that they cannot.

Titling a section of her Letter *Housing/Residential Care*, Mrs. Sanders writes that Chris has always lived at home and had a room to himself. She briefly describes the family home and the articles in the home that give Chris special pleasure, such as his portable radio.

She then describes his daily and weekly routine, including the fact that Chris finds great joy in going to dances each week at the local Arc. She briefly lists his favorite clothing, food, games, and so on. She also mentions that each year Chris visits his sister for a week in the summer.

Mrs. Sanders then considers what future living arrangements might be suitable for Chris, and she uses the worksheet on the next page to jot down three options. Before she transfers these options from the worksheet to her Letter of Intent, she discusses each one with Chris. She does so because he needs to be a key member of the team planning his future life.

Following her talk with Chris, Mrs. Sanders lists the agreed upon information in her Letter of Intent. The first option she lists is the possibility that Chris might live with his sister. As a second possibility, he might live with an old family friend. The third option is residence in a group home. Because this last option may indeed be the one that is finally selected for Chris, Mrs. Sanders takes care to describe the type of group home she thinks he would enjoy. As a mother and lifelong friend to Chris, she sees past his limitations to his strengths, and she notes these down in some detail. Lastly, she expresses her desire that the group home will give him room to grow and build upon those strengths.

Residential Care is just one important area for Mrs. Sanders to cover in her Letter of Intent. It takes her a week to complete the other sections. She finds that describing the past is not nearly as difficult as considering the future, but she methodically and systematically works her way through each area, using the worksheet when planning is necessary. The end result is a Letter of Intent that is twelve pages long, handwritten. She feels comfortable that anyone picking up this Letter of Intent will have a head start in getting to know and care for Chris.

What Happens Once the Letter of Intent Is Written?

Once you've written the Letter of Intent about your son or daughter, the first, most important thing to do is to *let people know that there is a Letter of Intent available to be consulted.* This might mean telling your other children (or relatives, neighbors, friends, workshop director, pastor, or case manager) why you have written the Letter, what type of information it contains, and where the Letter can be found. *Put the Letter in an easily accessible place, and make it clearly identifiable.* Many parents also make copies of the Letter and give it to their other children (or persons such as a neighbor).

Secondly, you should *update the Letter on a regular basis.* Select one day out of each year (such as the last day of school or perhaps your son or daughter's birthday) where you will review what you have written and add any new information of importance. Talk with your child each time and incorporate his or her ideas. After each addition, sign and date the Letter. Should something change in your son or daughter's life, such as his or her caseworker or the medication he or she is taking, update the Letter immediately.

In Conclusion...

Will your Letter of Intent overcome all of the obstacles to your son or daughter's transition into someone else's care? No, of course not. However, the Letter is of immediate usefulness in coping with your son or daughter's changed situation and, in the long term, will certainly help careproviders understand and care for your loved one.

Letter of Intent Worksheet:
Considering Your Son or Daughter's Future

For each applicable area below, consider your son or daughter's future. List 3-4 options to guide future caregivers in decision making and interaction with your child. Draw upon what you know about your son or daughter, through observation and through discussion with your child, and share what you've learned!

Residence: *If something should happen to you tomorrow, where will your son or daughter live?*

1. 2. 3. 4.

Education: *You have a lifelong perspective of your son or daughter's capabilities. Share it!*

1. 2. 3. 4.

Employment: *What has your son or daughter enjoyed? Consider his or her goals, aspirations, limitations, etc.*

1. 2. 3. 4.

Medical Care: *What has and has not worked with your son or daughter? What should future caregivers know?*

1. 2. 3. 4.

Behavior Management: *What consistent approach has worked best in your absence during difficult transition periods in your son or daughter's life?*

1. 2. 3. 4.

Social: *What activities make life meaningful for your son or daughter?*

1. 2. 3. 4.

Religious: *Is there a special church or synagogue or person your son or daughter prefers for fellowship?*

1. 2. 3. 4.

Additional Considerations

Advocate/ Guardian ***Who will look after, fight for, and be a friend to your son or daughter?*** **(List 3-4 options.)**

Trustee(s) ***Who do you trust to manage your son or daughter's supplementary funds?*** **(List 3-4 options.)**

FYI: Information Resources from NICHCY's Database

The following information was selected from numerous resources abstracted in ***NICHCY's*** database. If you know of a group that provides information or services about estate planning to families, professionals, or the general public, please send this information to ***NICHCY*** for our resource collection and database. We would appreciate this information and will share it with others who request it.

You can obtain many of the documents listed below through your local library. Whenever possible, we have included the publisher's address or some other source in case the publication is not available in your area. ***It is a good idea to contact the publisher or organization and obtain the latest information on ordering, payment procedures, and shipping and handling charges.*** The prices listed are, of course, subject to change without prior notice.

The organizations listed are only a few of the many that provide various services and information about estate planning to families and professionals. Additional publications and information may also be available from state and local parent groups and state and local affiliates of many disability organizations. Please note that the addresses and telephone numbers are subject to change without prior notice.

If you experience difficulty in locating these documents or organizations, or if you would like additional assistance, please contact ***NICHCY***. Finally, you may find ***NICHCY's*** *State Resource Sheet* for your state or territory helpful in contacting other resources of information.

PRINT RESOURCES

Apolloni, T., & Cooke, T.P. (Eds.). (1984). *A new look at guardianship: Protective services that support personalized living*. Baltimore, MD: Paul H. Brookes. (Available from California Institute on Human Services, Sonoma State University, Rohnert Park, CA 94928. Telephone: (707) 664-2416. Price: $25.00.)

Arc-Beaver County. (1989). *A guide to estate planning for the mentally retarded*. Monaca, PA: Author. (Available from the Arc-Beaver County, 1260 North Broadhead Road, Suite 103, Monaca, PA 15061. Telephone: (412) 775-1602.)

Arc-California. (1990). *Guardianship, conservatorship, trusts and wills for families with mentally retarded or other disabled family members* (4th ed.). Sacramento, CA: Author. (Available from the Arc-California, 120 I Street, 2nd Floor, Sacramento, CA 95814-2213. Telephone: (916) 552-6619. Price: $2.00.)

Arc-Indiana. (1988). *Future planning: Decisions by choice, not chance: An asset planning workbook for parents with a disabled child*. Indianapolis, IN: Author. (Available from the Arc-Indiana, 22 E. Washington Street, Suite 210, Indianapolis, IN 46204. Telephone: Outside of IN, call (317) 632-4387. Within IN, call (800) 382-9100. Price: $16.50, non-members; $11.50, members.)

Arc-Michigan. (1989). *Supplemental Security Income/Social Security disability: An advocate's manual*. Lansing, MI: Author. (Available from the Arc-Michigan, 333 South Washington Square, Suite 200, Lansing, MI 48933. Telephone: (517) 487-5426. Price: $12.00, non-members; $10.00, members.)

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ORGANIZATIONAL RESOURCES

The organizations listed below provide a variety of estate planning or lifetime care services. *Please note that listing these organizations does not imply endorsement by **NICHCY**; we provide the names for informational purposes only.* Families are encouraged to contact these organizations and request more information about their services. Your decision to participate in any program must be based upon your family's individual needs and situation and your understanding of the services that are offered.

The Arc (formerly the Association for Retarded Citizens) - National Headquarters, 500 E. Border Street, Arlington, TX 76010. Telephone: (817) 261-6003.

The Arc has affiliate offices throughout the United States. Many of these affiliates have developed state-specific guides and booklets pertaining to estate planning for parents who have a son or daughter with developmental disabilities and/or mental retardation. Many affiliates also offer guardianship or master trust programs, and may be able to recommend attorneys and/or financial planners with expertise in estate planning when a person with a disability is involved. Contact the National Headquarters to find out the name and address of the Arc affiliate nearest you, or contact your local Arc directly.

Estate Planning for Persons with Disabilities - Park Place, Suite 112, 3100 Arapahoe Avenue, Boulder, CO 80303. Telephone: 1-800-448-1071; (303) 449-4103.

EPPD serves as a national resource for parents and professionals on the highly specialized topic of estate planning for persons with disabilities. EPPD presents free two-hour educational seminars sponsored by local groups across the country in order to teach families how to do Life and Estate Planning. EPPD also trains attorneys and financial planners around the country in the specifics of estate planning for parents of sons and daughters with disabilities. This activity enables EPPD to put families in contact with professionals in their local area who have the specialized knowledge vital to preparing an estate plan that will protect the future of a person with a disability. Using a team approach, EPPD keeps the costs of estate planning down by contracting with the professionals involved for a package price, rather than through charging hourly rates. As of July 1992, there were over 96 teams in 44 states.

OTHER ORGANIZATIONS

Here is a listing of selected national organizations that can provide information, publications, brochures, or referral about estate planning. Many of these organizations focus upon a specific disability or disabilities and have affiliates at the state or local level. The affiliates may have publications specific to the laws of the state and may be able to refer families to local financial planners and attorneys specializing in estate planning when a son or daughter with a disability is involved. Call the national office to find out what information they have available on estate planning, as well as what affiliates exist in your state or locality.

Association for Persons with Severe Handicaps (TASH) - 11201 Greenwood Avenue North, Seattle, WA 98113. Telephone: (206) 361-8870.

Autism Society of America - 8601 Georgia Avenue, Suite 503, Silver Spring, MD 20910. Telephone: (301) 565-0433.

Life Services for the Handicapped, Inc., 352 Park Avenue South, Suite 703, New York, NY 10010. Telephone: (212) 532-6740.

Mental Health Law Project - 1101 15th Street N.W., Suite 1212, Washington, 20005. Telephone: (202) 467-5730.

National Alliance for the Mentally Ill (NAMI) - 2101 Wilson Boulevard, Suite 302, Arlington, VA 22201. Telephone: (703) 524-7600.

National Down Syndrome Congress - 1800 Dempster Street, Park Ridge, IL 60068-1146. Telephone: (708) 823-7550; (800) 232-6372 (Toll-free).

National Down Syndrome Society - 666 Broadway, Suite 810, New York, NY 10012. Telephone: (212) 460-9330; (800) 221-4602 (Toll-free).

National Easter Seal Society - 70 East Lake Street, Chicago, IL 60601. Telephone: (800) 221-6827 (Toll-free); (312) 726-6200; (312) 762-4258 (TT).

National Head Injury Foundation - 1776 Massachusetts Avenue N.W., Suite 100, DC 20036. Telephone: (202) 296-6443; (800) 444-6443.

National Mental Health Association - 1021 Prince Street, Alexandria, VA 22314-2971. Telephone: (800) 969-NMHA.

United Cerebral Palsy Associations, Inc. (UCPA), Community Services Division, 1522 K Street N.W., Suite 1112, Washington, DC 20005. Telephone: (202) 842-1266; (800) 872-5827 (Toll-free, except in Washington, DC).

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